

JACK BAILEY
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Calvert and St. Mary's Counties

Budget & Taxation Committee



THE SENATE OF MARYLAND
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Senate Bill 117 – Health - Newborn Screening Program - Krabbe Leukodystrophy

Dear Chair Beidle and Members of the Committee,

I am writing to introduce Senate Bill 117. This bill would require that Krabbe Disease be added to the Maryland Department of Health's newborn screening system.

Krabbe is a neurological disease caused by the absence of an enzyme which leads to the loss of myelin causing the nerves and brain to be unable to communicate. Symptoms begin mildly around 4-6 months of age but quickly progress to blindness, deafness, seizures, decreased mobility and eventually death. If detected at the beginning of life, Krabbe is treatable. Early detection of Infantile Krabbe Disease allows for a transplant which can dramatically improve the quality and longevity of the child's life. However, this operation can usually only be done before the child is six months of age. Far too often, by the time the child is diagnosed, it is too late for a transplant. Adding Krabbe to the newborn screening system will save the lives of children in our State.

Last month, the federal Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) recommended Krabbe be added to the Recommended Uniform Screening Panel for newborns. The Secretary of Health and Human Services will make the final determination, but Senate Bill 117 will allow Maryland to move forward without delay with this life-saving screening for newborns. Unfortunately, we have seen our State react slowly to the recommendations of the federal government in adding to our newborn screening system. In preparing to present this legislation, I was made aware of two other diseases that have been recommended by the ACHDNC but not added by Maryland's advisory committee, which is responsible for advising the Secretary of Health, who has the final authority to add these diseases to the newborn screening system in this State.

Eleven other states have instituted this screening. Nine of these eleven states have done so since the General Assembly last considered adding Krabbe to the screening system in 2014. These states did so before the federal advisory committee made their recommendations. We have more backing with regards to the scientific evidence than any of these other states had when they made their decision. It is time to add Infantile Krabbe Disease to the list newborn screening system.

I am submitting with this bill an amendment to specify that the bill applies to Infantile Krabbe Disease, to be consistent with the Federal recommendation. I respectfully request a favorable report with this amendment on Senate Bill 117. Thank you for your consideration.

Sincerely,

A handwritten signature in black ink, appearing to read "J. Bailey".

Senator Jack Bailey